



Canadian Hospice Palliative Care Association

Association canadienne de soins palliatifs

Themes

Ensuring that all Canadians and specific groups including children, Indigenous peoples, those with a disability and seniors in urban, rural and remote communities can access high-quality hospice palliative care in the setting of their choosing.

Executive Summary

The Canadian Hospice Palliative Care Association (CHPCA) and the Quality End-of-Life Care Coalition of Canada (QELCCC) have made significant progress advancing a community-integrated palliative approach to care in Canada through the Government of Canada funded initiative – *The Way Forward*. Acting as a ‘catalyst project’, *The Way Forward* has engaged provincial and territorial governments, health system planners and policymakers, health-care professionals, and Canadians to help improve the understanding and awareness of aging, living with chronic life-limiting illnesses, hospice palliative care (HPC) and advance care planning (ACP).

CHPCA believes there is an ongoing and pivotal role for the Government of Canada to bring national leadership, enhanced coordination and continued engagement with Canadians through a second phase of work.

A 2014 Harris/Decima survey found that a large majority of Canadians (73%) feel that governments place too little priority on end-of-life care, including over one-third (35%) who feel that it is far too little.¹ That percentage is likely much higher in the wake of the successful passage of Medical Assistance in Dying (MAID) legislation, which brought to light the deficiencies in equitable national access to hospice palliative care services.

While it is acknowledged that the implementation and delivery of hospice palliative care generally falls to provincial and territorial governments, there is a pressing need for national leadership on this file. Efforts to raise awareness among Canadians about palliative care and planning for end-of-life care through advance care plans remains a key priority. Continuing to support implementation of the action steps identified in the national framework developed by *The Way Forward* with consistent tools and resources is equally important.

In addition to improved access to HPC, many Canadian families have not discussed their end-of-life care wishes, although they understand the importance of doing so. With strong public support for discussions about palliative and end-of-life care, the creation of a national campaign to disseminate information, providing tools and resources that will encourage and facilitate end-of-life care conversations for Canadians will help improve awareness of our options.

¹ A quantitative online research survey of 2,976 Canadian adults. Completed using Harris/Decima’s proprietary online panel so is precluded from reporting a margin of error. Data were collected between July 5 and August 7 2013. Survey data were weighted using 2011 Census to reflect general population (gender, age and region).



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Definitions:

Hospice palliative care (HPC) aims to relieve suffering and improve the quality of living and dying. It strives to help patients and families address physical, psychological, social, spiritual and practical issues, and their associated expectations, needs, hopes and fear. It helps prepare for and manage self-determined life closure and the dying process. It helps patients and families cope with loss and grief during the illness and bereavement. HPC is appropriate for any patient and/or family living with, or at risk of developing, a life-threatening illness due to any diagnosis, with any prognosis, regardless of age, and at any time they have unmet expectations and/or needs, and are prepared to accept care. HPC may complement and enhance disease-modifying therapy or it may become the total focus of care. HPC is most effectively delivered by an interdisciplinary team of healthcare providers who are both knowledgeable and skilled in all aspects of the caring process related to their discipline of practice.

Advance Care Planning (ACP) is a process of reflection in which a person with decision-making capacity expresses their wishes regarding their future health care in the event that they become incapable of consenting to or refusing treatment or other care. The process includes conversations with family and friends, and particularly the person who will act as a substitute decision maker and with the person's health-care providers and perhaps with lawyers who prepare wills and powers of attorney.

The Palliative Approach is described as an approach to care focused on improving the quality of life of persons and their families who are aging or living with chronic conditions. It involves physical, psychological, social, and spiritual care provided in all settings. The palliative approach is not delayed until the end stages of an illness but is applied earlier to provide active comfort-focused care and a positive approach to reducing suffering. It reinforces the person's autonomy and right to be actively involved in his or her own care - and strives to give individuals and their families a greater sense of control by making informed care choices. Health care providers in the primary care or community setting, occasionally supported by specialist palliative care teams when needed, deliver care in a wide variety of settings from a patient's home or in long-term care facilities, to hospitals in cities, rural communities and remote areas.

Proposal 1: Making Advance Care Planning Matter

Current research clearly shows that ACP results in increased patient and family satisfaction, less stress and anxiety for families and caregivers, an improved quality of life and death, fewer decision-making conflicts, fewer medical interventions and more appropriate use of health care resources in the final weeks of life. Yet, less than half (49%) of Canadians have discussed end-of-life care with a family member, only 9% have discussed it with a healthcare professional, and 80% do not have a written plan for their care. The national consultations conducted through *The Way Forward* identified ACP as central to facilitating the introduction of an integrated palliative approach to care. ACP is attracting some attention nationally, and a number of provinces are starting to work on spreading the CHPCA-led national "Speak Up" campaign. However much more is needed to ensure that all Canadians develop their advance care plan while they are healthy and revisit their goals over time with their families and health-care providers throughout the trajectory of illness or aging.



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Proposed Activities

The CHPCA proposes coordination of an 'Advance Care Planning in Canada' campaign, which would aim to raise public and health professional awareness of the importance of advance care planning. The targets would be the general public and caregivers, and those working in health systems and the community who support aging and/or chronically ill Canadians and their families. Health care professionals, government officials, and private sector corporations would be important stakeholders. We hope to foster partnerships across Canada with governments, professional groups, non-government organizations, corporate Canada and communities.

The "Speak Up" campaign and National ACP Day (April 16) are growing, but the initiative would benefit from a better-coordinated and broader awareness campaign to reach the intended audiences. Materials would be co-branded with the Government of Canada to emphasize the leadership that the federal government is undertaking on behalf of all Canadians. Using existing materials, we can ensure national consistency and facilitate partnership adoption and local or regional adaptation. Funding would also support the development of national awareness tools. These tools would be developed in consultation with professionals and Canadians, including with and for First Nations, Inuit and Métis peoples. Since the legal construct is different in each province/territory, and there are also important issues of cultural-safety, and templates would be developed that can be customized depending on the jurisdiction. The funding would also support development of electronic resources that can be easily used by all stakeholders including videos, mobile apps, interactive online resources and training modules. A national repository of all resources will be available to both professionals and the general public on www.advancecareplanning.ca.

Project Goal

The ultimate goal of ACP in Canada is to raise awareness that planning appropriately for a serious illness or aging will improve health care outcomes and help families through a vulnerable time. Engaging community partners will improve best practices, tools and resources available to all Canadians. The CHPCA and its partners can encourage proper planning and decrease costly and unnecessary hospitalizations and emergency room visits and other avoidable crises that occur when families are faced with difficult decisions at the end of life.

Collaborators and Partners

- Canadian Hospice Palliative Care Association (proposed recipient).
- ACP in Canada Task Group

Budget

\$3-5 million over 3 years. The cost depends on the reach of the national campaign aimed at Canadians. This should be targeted at times of health transition or when patients are given a life threatening diagnosis.



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Proposal 2: Moving *The Way Forward* into Action: Phase II

From 2012-2015, the activities of *The Way Forward: An Integrated Palliative Approach to Care* focused on working with numerous stakeholders including provincial and territorial governments, regional health systems, policymakers and program planners, national professional and patient organizations to develop a practical and applicable framework for action.

We have developed the road map in the national framework, yet there continues to be a need to raise awareness and accelerate the adoption across settings of care. An Ipsos Reid Survey commissioned by *The Way Forward* found that family physicians and nurses in primary care are very supportive of the health system and patient benefits of hospice palliative care, yet only 25% are comfortable providing palliative and end-of-life care.ⁱ

Based on the research, there are several gaps to fill with support, education and resources that would benefit family physicians, nurses and their patients including:

- Overall comfort level in discussing palliative care and end-of-life issues
- Initiating discussions about a palliative approach and hands-on experience with ACP
- Managing challenging issues such as control of pain and depression
- Identifying resources in the community to provide support to patients and families

Through the ongoing funding of phase II of *The Way Forward*, the Government of Canada can continue to play a leadership role. A palliative approach to care across health systems will allow the ability to measure and report on progress. In turn, governments can better manage healthcare priorities and pressures, including the growing costs of providing care at end-of-life, particularly as the Canadian population ages.

Proposed Activities

Additional funding would assist in further disseminating adoption and adaptation of the national framework and promoting policy and practice change across health systems, including with and for First Nations, Inuit and Metis. Proposed activities would support exploring models that integrate a palliative approach to care while building in mechanisms to support long-term sustainability.

Based on Phase I of *The Way Forward*, quality improvements will be identified across all settings of care through a series of indicators. Establishing standardized models will be especially crucial for Canadians and their families in home care, long-term care, and in Aboriginal, rural, and remote communities. These would be developed in collaboration with national bodies such as Accreditation Canada and the Canadian Institute for Health Information.

Project Goal

As the Harris/Decima survey demonstrated, three-quarters of Canadians would turn to their family physician (FP) for more information about hospice palliative care services and ACP. Yet a recent Ipsos Reid survey of FPs found that 52% of FPs had some experience and were not very comfortable with these conversations, and a further 24% had no experience and were not comfortable.



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Our goal is to facilitate access, awareness and understanding of the palliative approach to care, across all settings of care, by training and educating physicians and other health care professionals. This will ensure they are prepared to assist patients with chronic and life-limiting illnesses or who are aging, to live well until death.

Collaborators and Partners

Canadian Hospice Palliative Care Association and the QELCCC, working with pan-Canadian stakeholders.

Budget

\$6 million over 3 years.

Word Count: 1855